Commentary

Health Decisions Movement

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Many have heard of the Oregon Health Plan, an attempt to allocate scarce medical resources based on current medical knowledge and community health values. Some are acquainted with Oregon Health Decisions, the citizen-based organization that in part developed the plan. Perhaps more have heard of American Health Decisions, the confederation of state health decisions organizations from California to Vermont. I describe the balance of facts and values that underlie setting priorities for the delivery of health care.

The health decisions movement originated as a response to the lack of a fair and prudent health policy in the United States. For example, the simple question "Should more public funds be invested in health promotion relative to those invested in curative medicine?" goes unanswered for the lack of expressed public consensus. In pursuit of balanced health policy, the health decisions movement undertakes to articulate grass roots health values through consensus-seeking community meetings.

Each of 16 affiliated state citizen organizations currently making up the health decisions movement sponsors community meetings, study groups, forums, and literature related to health care delivery. The mission is civic action in health care based on expressed community values. To accomplish this, relevant issues are placed before interested persons for discussion leading to consensus on community values. As consensus develops it becomes the focus of public education and organization directed at constructive health policy. Generally, with consensus on an issue, such as curative versus preventive medicine, the next step is integrating the determined values into the present system by sharing the consensus as well as its relation to relevant issues—cost, treatment procedures, capital investment, populations affected—with policymakers.

The health decisions movement wrestles with important cultural issues such as why health care delivery in our country is such a pressing dilemma while in Canada or most Western European countries, most persons appear reasonably content with their system. The answer turns out to be complex, stemming from two related reasons: In the United States an independent public is actively suspicious of government programs, and the average American has a remarkably strong belief in personal choice.

One complication for the American philosophy of personal independence is a common wish to rescue the unfortunate. Traditionally, regardless of cost, the public is willing to go to extraordinary lengths to rescue a child "trapped down a well." This speaks to an implicit public value for some form of community response.

On the other hand, as a nation we seem much less willing to sacrifice time, money, and emotion for those who suffer unseen, without benefit of outspoken advocates or media hype. To cover this discrepancy between expressed concern and practiced denial, particularly in health care, we assume the government, which from another perspective we view with suspicion, will care for those whose needs, including medical, are less apparent and heartrending. Yet any such government effort, as shown by experience, calls for the setting of priorities in allocating limited health care resources. At this point our rescue philosophy runs counter to our personal choice philosophy.

Confronted with the conflict in values, the public, along with our leaders, fearing an infringement on personal choice, becomes reluctant to undertake any form of explicit setting of priorities for health care allocation. The block comes when the rescue philosophy confounds civic action by swiftly reducing public consideration of priority setting to a matter of deciding life and death. Under such circumstances, so commonly experienced, developing community consensus on priorities demands sophisticated and sustained consideration, or so it seems to the health decisions movement.

The health decisions movement assists the public in clarifying health care values beyond rescue circumstances in relation to larger issues rapidly evolving through medical innovation, a declining economy, an increasing tax burden, and fiercely competing social needs. Here the interplay between facts and values becomes the heartbeat of the health decisions movement.

Every success of the health decisions movement rests on the ability to listen to and appropriately respond to concerned people. We listen in three ways: randomly, to particular groups, and to the community in forum. Perhaps least appreciated is the random listening that has sparked many state health decisions organizations. As concerned persons sharpen their ears to expressed suffering arising from inequities in the delivery of health care, by the inappropriate use of medical technology, or by the waste of valuable resources, they resolve to act. Random

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listening has identified initial cadres of health decisions organizers and workers.

The second way we listen is to existing organizations expressing their concern about mindless or harmful directions health care sometimes takes. We pay attention to actual conditions reported by first-line participants. Voiced distress prompts health decisions organizations to initiate study groups, education programs, and community projects that produce grass roots response available to policymakers and legislators. Valuable information secured in this fashion generally tends to be information and facts about cases and conditions rather than expressed underlying values.

The second way of listening also includes polling the public. Opinion polls have a surprisingly short shelf life, however, largely because responses are not generated by thoughtful discussion and considered reflection of personal values. Knowing that a certain part of the public is in favor of a particular program does little to clarify how this opinion relates to integrated values. In contrast, expressed values, such as those a community places on prenatal care as a considered investment in the future, are more important in determining policy.

The third, and unique, form of listening involves collecting, clarifying, articulating, and carrying community values from public forums. Health decisions organizations organize community meetings offering citizens a forum to voice their health care values. Neighbors can speak and listen. Pertinent questions arise from half-thought-through ideas. Thus critical personal judgments evolve, reflecting deeper principles than could be elicited by passive attendance at an expert's lecture followed by a poll.

At a health decisions forum citizens are not asked if they support or oppose a particular program or aspect of health care. Rather, they are presented with relevant problems, such as whether persons over the age of 75 should receive organ transplants when the cost is high and organs scarce. The goal is not determining the eligibility age for organ recipients but finding out the values the participants use in arriving at their decisions. The search is for an understanding of the basis of their judgments. The value results are then returned to the group to establish a commonality, a consensus, of expressed values.

Our fact-or-value approach, through open community discussion, places the rescue philosophy into a perspective for respectful consideration while preventing it from preempting the work of setting priorities for health care. The question of rescue is transformed into determining how much value the community places on a life jeopardized by a crisis versus a life jeopardized by day-to-day circumstances.

By listening in all three ways, the health decisions movement serves the public's need for participant responsibility in our health delivery system. Only as we clarify, classify, and publish the values of our communities, states, and nation do we enable our political leaders to wisely and carefully weigh expert knowledge with the public's values in establishing health policy. Clarification of community values offers a way through the present maze of conflicting demands and proposals burdening and confusing the delivery of health care.